

NEW JERSEY STATE CANCER REGISTRY

**ABSTRACT INSTRUCTION MANUAL FOR
PHYSICIANS, AMBULATORY CARE CENTERS &
RADIATION TREATMENT FACILITIES
2008**

**CANCER EPIDEMIOLOGY SERVICES
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TRENTON, NJ 08625-0369
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Jon S. Corzine
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INTRODUCTION TO THE NEW JERSEY STATE CANCER REGISTRY

The New Jersey State Cancer Registry (NJSCR) is a population-based incidence registry and includes all cancer cases diagnosed in New Jersey residents since October 1, 1978. The NJSCR serves the entire state of New Jersey, which includes a population of approximately 8.4 million people.

The purpose of the NJSCR is to track incidence in an effort to promote the following activities: scientific research; public and professional education programs; planning, implementation and evaluation of cancer control; and prevention activities. The NJSCR has been recognized for its high-quality data, and we continue to strive to improve the quality and enhance the usefulness of the data.

The NJSCR was established by legislation (NJSA 26:2-104 et. seq.) in 1977 in response to concern that New Jersey was suffering from the highest cancer mortality rates in the country. New Jersey regulations require the reporting of all newly-diagnosed cancer cases to the Registry within six months of diagnosis. All primary malignant and in situ neoplasms are reportable to the NJSCR, except in situ and localized basal cell and squamous cell carcinomas of the skin and carcinoma in situ of the cervix (since 1995). Benign and borderline intracranial and Central Nervous System tumors are reportable if diagnosed January 1, 2004 and later. Certain benign and borderline diseases of other sites are also reportable to the NJSCR; please refer to the Cancer Reporting Statute. Health care facilities, physicians, dentists and independent laboratories file reports with the NJSCR. In addition, reporting agreements are maintained with neighboring states so that New Jersey residents diagnosed in facilities out of state are identified.

The information collected by the NJSCR includes the following: demographic characteristics of the patient, medical information on each cancer such as primary site, histologic type, collaborative stage and treatment information. The vital status of each patient is followed annually until death. The cause of death is also incorporated into the data set when the information is available.

In February 2001, the NJSCR became a Surveillance, Epidemiology and End Results (SEER) Registry. The SEER Program of the National Cancer Institute is the most authoritative source of information on cancer incidence and survival in the United States. SEER currently collects and publishes cancer incidence and survival data from population-based cancer registries covering 26% of the US population. Geographic areas selected for inclusion in the SEER Program is based on the registries' ability to operate and maintain a high-quality population-based cancer reporting system and for their epidemiologically significant population subgroups.

The NJSCR also participates in the National Program of Cancer Registries (NPCR), established by the Centers for Disease Control and Prevention (CDC) in 1992 by the Federal Cancer Registries Amendment Act (Public Law 102-515). NPCR promotes statewide, population-based registries to collect uniform data elements in a standardized format. The NJSCR is also a member of the North American Association of Central Cancer Registries (NAACCR) which is a professional society established in 1987. NAACCR is interested in the ongoing development of cancer registries and the establishment of registry standards.

CONFIDENTIALITY

The New Jersey Cancer Registry Statute N.J.S.A.26:2-107 states that reports of individual patients made to the NJSCR are held in the strictest confidence. Reports made pursuant to this act are used only by the Department of Health and Senior Services and such other agencies as designated by the Commissioner of Health and Senior Services. N.J.S.A.26:2-108 states that no individual or organization providing information to the Department of Health and Senior Services in accordance with this act shall be held liable for divulging confidential information. Please note: reporting information about cases of cancer in accordance with the NJSCR authorizing statute and regulations is permitted by the Health Insurance Portability and Accountability Act. The privacy rule contains a specific provision authorizing covered entities to disclose protected health information as required by law. Public Health reporting under the authority of the State law is specifically exempted from the Privacy Rule Regulations 45CFR154.512(6)(I)(i). A copy of the Cancer Reporting Statute, Regulations and listing of Reportable Diseases and Conditions Reportable List can be referenced at the end of this manual.

HOW TO REPORT TO THE NJSCR

Physicians, labs, ambulatory centers, and radiation treatment facilities are also responsible for reporting cases. A cancer registry abstract form must be completed for each cancer patient diagnosed, and/or treated in a health care facility (including labs, ambulatory centers and radiation treatment centers). Physicians must report all non-hospitalized patients, including those with pathology diagnosis from independent labs.

A separate abstract must be completed for each primary malignancy, or reportable disease or condition. An abstract should be filled out and submitted to the NJSCR within six months of diagnosis. Please be legible when completing the forms. Make sure that every item is filled in. A sample of the form can be found at the end of this manual. Please send completed forms to:

New Jersey State Cancer Registry
Cancer Epidemiology Services
NJ Department of Health and Senior Services
PO Box 369
Trenton, NJ 08625-0369
Phone (609) 588-3500
Fax (609) 588-3638

REPORTABLE CASES

A cancer case must be reported to the NJSCR if a patient meets the following criteria:

- ✓ All cancer cases must be reported by ambulatory care centers, radiation treatment facilities, and hospice programs. Physicians must report all non-hospitalized patients.
- ✓ Cases must be reported within six months of diagnosis.
- ✓ All reportable cases **diagnosed on or after January 1, 1979** must be submitted.
- ✓ If the following ambiguous terms are used to describe a cancer, it must be reported: **apparent(ly), appears, appears to, comparable with, malignant appearing, consistent with, most likely, probable, suspected, suspicious, presumed, favor(s), typical of.**
- ✓ Patients with a **clinical diagnosis of cancer**, which was based on clinical judgment, must be reported.
- ✓ If more than one primary disease occurrence cancer is diagnosed in a patient, **a separate report must be submitted for each primary malignancy**, or reportable disease or condition).
- ✓ Basal and squamous cell skin carcinomas of the lip, anus, vulva, vagina, penis or scrotum, must be reported.
- ✓ Basal and squamous cell skin carcinomas of the skin are reportable only if regional or distant spread is present at diagnosis.
- ✓ Any **benign tumor** of the Central Nervous System including the brain, meninges, spinal cord, cranial nerves, pituitary gland, craniopharyngeal duct, pineal gland diagnosed on or after January 1, 2004 are reportable.
- ✓ Certain benign (O) and borderline conditions (+) are reportable. Refer to the listing of Reportable Diseases and Conditions at the end of this manual for these conditions.
- ✓ **Consult-only cases are reportable.** A consult may be done to confirm a diagnosis or treatment plan.
- ✓ New Jersey residents and non-residents must be reported including residents of foreign countries. If patient was diagnosed in a foreign country, please indicate this on the abstract, along with the name of the country, if known.

DEMOGRAPHIC INFORMATION

Please provide the following patient information. Accurate demographic information will enable the registry to create new case reports and/or match your submission to previous, concurrent or future reports.

Patient's Name

Record your patient's last name, first name and middle name.

Date of Birth

Record the exact date of the patient's birth in month, day, century and year.

Social Security Number

Record the nine-digit Social Security number.

Medicare claim numbers with a suffix "A" may also be entered in these fields.

Do not record spouse's Social Security number or those ending with B or D.

Patient's Address at Diagnosis

Record the number and street address of the patient's residence when the cancer was first diagnosed and treated. If the patient has multiple cancers, the address may be different for each primary. Use actual street address and avoid PO box in address. If the patient's residence is a long-term care facility, please record the name and address of the facility.

City, State, ZIP Code

Record the city, state, and zip code of the patient's residence at the time when the cancer was first diagnosed and treated.

Race and Ethnicity

Record the race of the patient. Every attempt should be made to record the correct race code. Indicate if the patient is of Spanish / Hispanic origin.

Marital Status at Diagnosis

Record the patient's marital status at the time when the tumor was first diagnosed and treated.

Sex

Record the patient's sex: male, female, other (hermaphrodite), transsexual.

Occupation

Record the patient's usual occupation. The usual occupation refers to the type of job the individual performed during most of his/her working life.

Industry

Record the type of activity conducted by the business/industry where the patient was employed for the longest time before the diagnosis of his tumor.

TUMOR INFORMATION

The following information identifies the type and location of cancer with which your patient was diagnosed. Please provide complete and accurate information on the type and location of cancer for each patient's abstract. *Please submit a pathology report if available.*

Primary Site/Laterality of This Cancer

The primary site is the anatomical location of tumor origin; the metastatic site is the area of the body where the tumor has spread to. **Be careful not to record the metastatic site.** Review all reports in the patient's medical record and record the most accurate statement for primary site and laterality. **Laterality** refers to the side of the body in which the cancer originated for sites with paired organs (e.g. left lung, right kidney). It applies to the primary site only.

Histologic Type of This Cancer

Record histologic type including the grade or degree of differentiation as stated in the FINAL pathologic diagnosis. If a diagnosis indicates two different grades or degrees of differentiation (such as "well and poorly differentiated"), record the higher grade.

Date This Cancer Was First Diagnosed

Record the first date a diagnosis of cancer was made. Please include the month, day, century, and year.

Initial Visit for This Cancer

Please record the initial month, day, century, and year that this patient was seen in your office with this cancer diagnosis.

Date of Last Contact

Please record the last date of contact with this patient (i.e., office visit, lab report or other physician's report). If the patient is deceased, please record date of death.

TNM Classification

The TNM Classification is based on the evaluation of the primary tumor (T), regional lymph nodes (N), and distant metastasis (M). Stage Group (Stage 0-4). For information regarding the use of TNM staging refer to AJCC Cancer Staging Manual, sixth edition.

Tumor Size

Record the largest dimension or diameter of the primary tumor in millimeters. For melanoma of the skin, please record the depth and thickness also.

Tumor Markers

Record the date, name and results of any tumor marker studies that have been done.

LDH Serum Results

Record the results of LDH assay.

Clinical Lymph Node Status at Diagnosis

Please record clinical assessment of lymph nodes prior to definitive treatment.

TREATMENT INFORMATION

Did This Patient Receive Any Treatment For This Cancer?

Please indicate whether the patient has received or is currently receiving any treatment for this cancer. If treatment was or is currently being received, please ***specify the type and date treatment was initiated.***

Surgery

Record the date and type of cancer-directed surgery performed. An excisional biopsy is cancer-directed surgery. Review the operative and pathology report and record surgical procedures performed. ***If reporting melanoma excision or re-excision record whether margins are negative and if the negative margins are greater than 1 cm.***

Radiation

Record the date, type, amount, and duration of radiation administered to the primary or metastatic site. Radiation treatment includes include external beam radiation, x-ray, cobalt, linear accelerator, stereotactic radiotherapy, brachytherapy, Gamma Knife, radioactive implants, and radioisotopes.

Chemotherapy

Record the date, type, and duration of chemotherapy administered to the patient. Record the generic or trade names of the drugs used for chemotherapy. Record combination therapy abbreviations.

Hormone/Other Therapy

Record the date, type and duration of therapy administered to the patient.

- Hormone therapy such as antihormones, endocrine surgery, and endocrine radiation therapy.
- Immunotherapy such as biological response modifier therapy, bone marrow transplant, and stem cell transplant.
- Other cancer-directed therapy that is not defined under Surgery, Radiation, or Chemotherapy, such as bone marrow transplants.
- Double-blind clinical trial, code not yet broken.
- Unproven therapy.

Referred to:

If you have referred this patient to another physician for treatment of this cancer, please provide the name of the hospital and/or physician. Please include physician's address telephone and fax number.

Date Completed:

Record the date you completed the reporting form and submitted to the NJSCR. Check

the method used to submit your case to the NJSCR. Fax completed form to (609) 588-3638. Mail your completed reports to New Jersey State Cancer Registry.

For further information concerning cancer reporting and our publications, please contact the following:

New Jersey State Cancer Registry
Cancer Epidemiology Services
NJ Department of Health and Senior Services
PO Box 369
Trenton, NJ 08625-0369
Phone (609) 588-3500 Fax (609) 588-3638

Please visit our website to obtain additional reference material, up-to-date cancer statistics and to obtain additional information about our surveillance activities:

<http://www.state.nj.us/health/ces/>

Additional report forms are also available on our website:

<http://www.state.nj.us/health/ces/njsr.shtml>

The AJCC Cancer Staging Manual, sixth edition can be ordered from the following website:

<http://www.cancerstaging.net/>